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AUTHOR Schalock, Robert L.; And Others
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ABSTRACT

The study obtained cross-cultural measures of quality of life (QOL), based upon perceptions of individuals with mental retardation/developmental disabilities (MR/DD) of their degree of satisfaction, productivity, independence, and community integration. The Quality of Life Questionnaire was administered to 92 persons in MR/DD programs in Australia, the Federal Republic of Germany, Israel, and the Republic of China and 552 persons from MR/DD programs in Nebraska and Colorado. A very consistent trend was found across the five countries: quality of life scores increase as one lives and works in more normalized environments. The paper also outlines characteristics of mental retardation/developmental disabilities services in the four countries (excluding the United States), focusing on: public laws regarding services to persons with MR/DD, funding patterns, administrative structures for MR/DD services, current living options, and current employment options. The paper notes that the concept of quality of life in habilitation services can be used cross-culturally to foster international QOL-oriented public policy, implement QOL-oriented program practices, and complete QOL-focused cross- cultural research projects. Includes 16 references. (JDD)

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AN INTERNATIONAL PERSPECTIVE ON QUALITY OF LIFE MEASUREMENT AND USE

Robert L. Schalock, Edward Bartnik, Fang Wu,
Andreas Konig, Chun-Shin Lee, Shunit Reiter[a]

The 104th Annual Convention of
The Association on Mental Retardation
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The concept of quality of life (QOL) has recently become an important national and international issue in the field of mental retardation and developmental disabilities. There are a number of reasons for this interest, including concern that many feel about the quality of life of disabled persons, the demonstration that social environments have considerable impact on an individual's lifestyle, the fact that complex programs require complex outcome measures, the reemergence of the holistic health perspective, and the concern that many people have about how others find satisfaction and life quality in a rapidly changing world (Donegan & Potts, 1988; Goode, 1988; Schalock, 1990).

Today's presentation represents a first generation attempt within the mental retardation/developmental disabilities field to obtain cross-cultural measures of QOL based upon persons' perceptions of their degree of satisfaction, productivity,

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independence and community integration. It is important to place this effort within the larger concept of social ecology and the impact that one's culture has on one's perceived quality of life. Our premise is that ecological comparisons across cultures to determine how characteristic of those cultures impact one's quality of life is the heart of a research strategy for studying the ecological aspects of a person's quality of life.

In addition to presenting cross-cultural QOL measures, the presentation also summarizes five characteristics regarding MR/DD services in Australia, The Federal Republic of Germany, Israel and The Republic of China. These five characteristics include: (1) public laws regarding services to persons with mental retardation/developmental disabilities; (2) funding patterns for these persons; (3) administrative structures for MR/DD services; (4) current living options; and (5) current employment options.

Quality of Life Conceptual Model

The QOL model we used in this cross-cultural study is based on the seminal studies of the quality of American life by Campbell, Converse and Rogers (1976) and Andrews and Whithey (1976). The model views a person's perceived quality of life as a resultant of three levels of life experiences including: (1) personal characteristics and objective life conditions in various life domains; (2) the perceptions or mind sets of significant persons and services about persons with disabilities; and (3) one's personal beliefs about what is

important and how the world works. Our working model is presented in Figure 1. The following paragraphs explain each

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Refer to Figure 1

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component of the model in more detail.

1. Personal characteristic and objective life conditions. This part of the model is based on a number of studies reporting the experience of one's general well-being is the product of personal characteristics, objective life conditions in various life domains, and satisfaction with life conditions in these various domains. For example, Campell et al (1987) report that factors such as marriage, family life, health, neighborhood, friendships, housework, jobs, housing, standard of living, amount of education, savings and membership in organizations are highly related to personal satisfaction and a perceived quality of life. Similarly, our own work (Keith, Schalock & Hoffman, 1986; Schalock, Keith, Hoffman & Karan, 1989) with persons with disabilities has found that measured quality of life is positively related to cognitive level, normalized living and work environments, family involvement, income, and the number of disabilities.

2. Perceptions or mind sets about persons with disabilities. One of the most significant changes of late has been people's attitudes about the ability and potential of persons with disabilities. This part of the model stresses

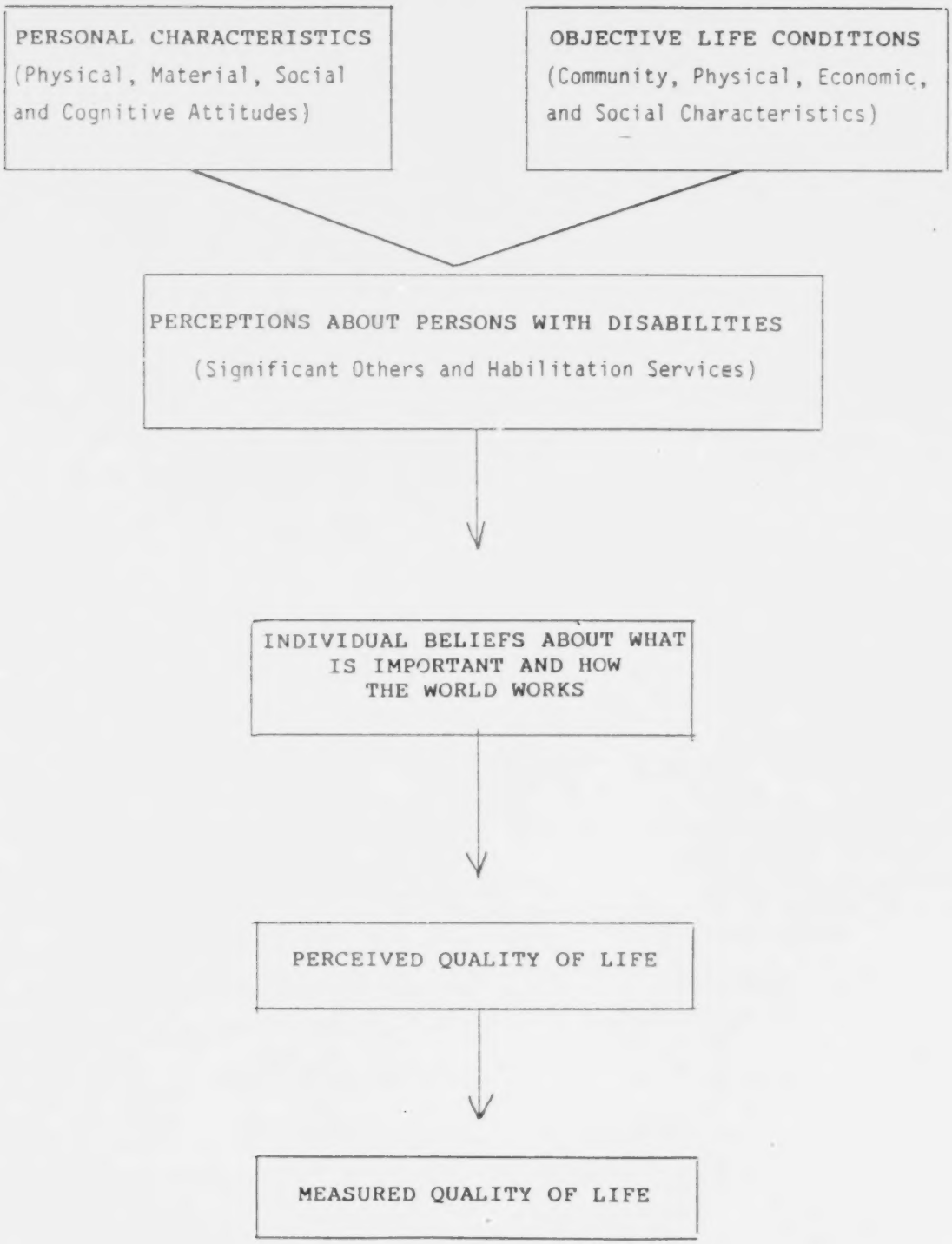
PERSONAL CHARACTERISTICS
(Physical, Material, Social and Cognitive Attitudes)
OBJECTIVE LIFE CONDITIONS
(Community, Physical, Economic, and Social Characteristics)
PERCEPTIONS ABOUT PERSONS WITH DISABILITIES
(Significant Others and Habilitation Services)
INDIVIDUAL BELIEFS ABOUT WHAT IS IMPORTANT AND HOW THE WORLD WORKS
PERCEIVED QUALITY OF LIFE
MEASURED QUALITY OF LIFE

FIGURE 1. QUALITY OF LIFE CONCEPTUAL MODEL

that the perceptions or mind sets about persons with disabilities exhibited by parents, peers, and friends (that is, significant others) as well as personnel within educational and habilitation services have a profound influence on the person's perceived quality of life. Specifically, we suggest that these perceptions and expressed attitudes act as intervening variables to effect the person's internal standard, which is used to judge the quality of life experiences and to develop personal beliefs about how the world works. Due to recent changes in perceived value and opportunities for persons with disabilities, we have all seen persons enter into the mainstream of life and report an enhanced quality of life (see for example, Schalock, 1990). Thus, it is evident that the internal standard against which QOL judgments are made is subject to modification related to life changes, and that any QOL model needs to reflect this dynamic, interactive process.

3. Personal beliefs about the world. Everyone has beliefs about how the world works in the physical, social, economic, and political realms. Our conception is that these beliefs stem from the two previously discussed levels of life experiences and the resultant internal standard against which persons make QOL judgments.

It is also apparent that each society has a structure of dominant beliefs that shape the way people in that society interpret the world with which they interact. Cross-cultural as well as within-cultural examples are plentiful. In reference to persons with disabilities, for example, some cultures are accepting and supportive, while others are rejecting and

exclusionary. The point that we want to stress in reference to this aspect of the QOL model is that society does change, and societal relearning is always taking place. The best examples of this relearning has been the evolving societal philosophies regarding normalization, advocacy, public laws, and the emphasis on the least restrictive environment (Schalock & Kiernan, 1990). Thus, one's personal beliefs about how the world works -- and the resultant quality of life judgments -- are influenced by the opportunities we are afforded and the experiences that accrue to these opportunities.

4. Perceived quality of life. Quality of life is necessarily subjective and cannot be inferred strictly from objective measures of conditions. In fact, there is general agreement that subjective and objective measures of QOL do not correlate highly, and that a valid conceptualization of QOL requires the thorough study of both objective and subjective factors (Lehman, 1988; Milbrath, 1982).

The Measurement of Quality of Life

The recent attempts of social scientists' to measure QOL fall within three large areas including psychological well-being, personal satisfaction, and social indicators. These areas, as related to the QOL model shown in Figure 1, are shown in Figure 2.

Refer to Figure 2

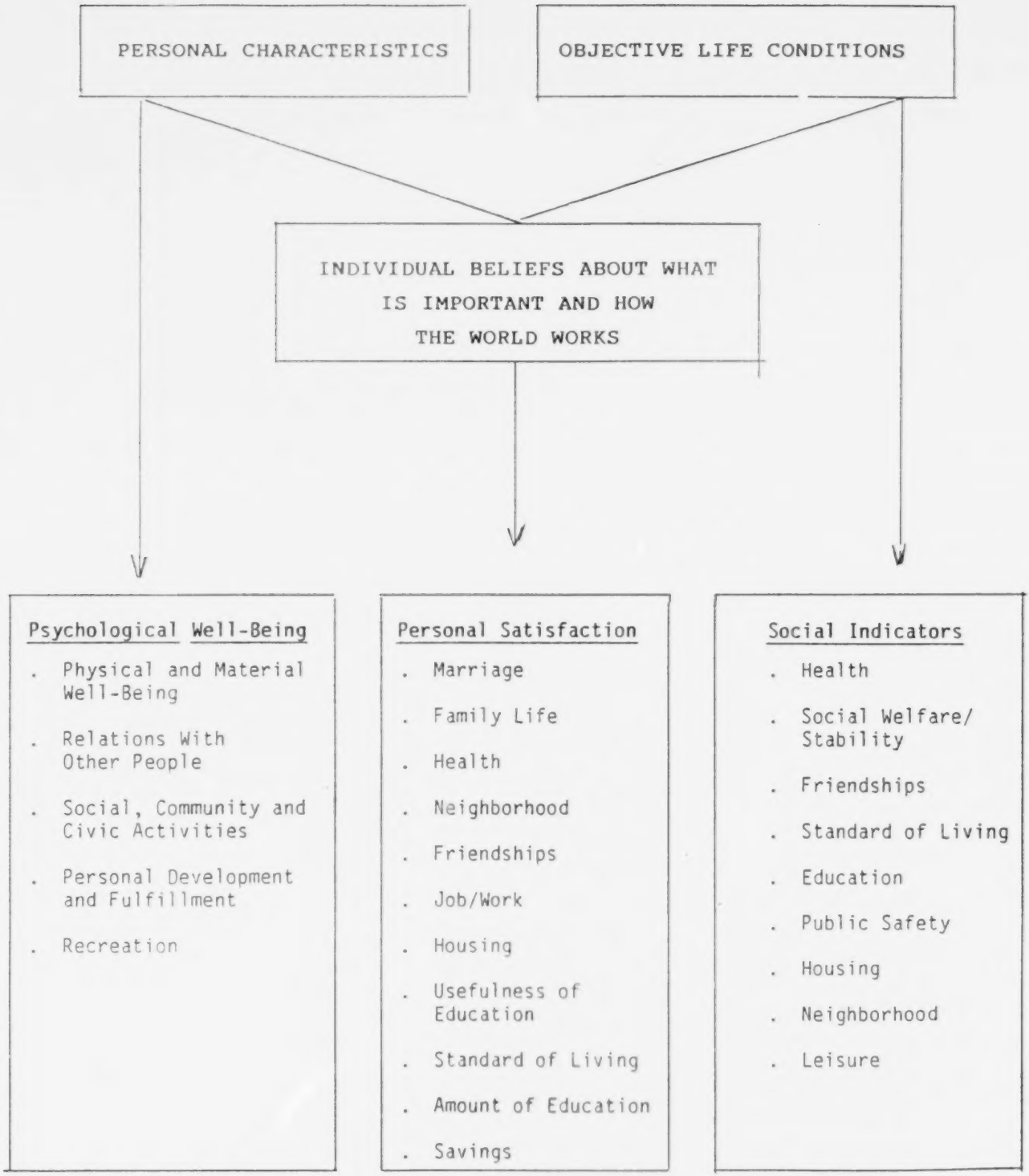

FIGURE 2: APPROACHES TO QUALITY OF LIFE MEASUREMENT

We have based much of our approach to the measurement of QOL for persons with disabilities on the three approaches to QOL measurement summarized in Figure 2. For example, we have encorporated into the 1990 QOL Questionnaire many of the items listed within the psychological well-being and personal satisfaction boxes. We have also encorporated most of the social indicators into the demographic profile of respondents so that these indicators can be used statistically as explanatory variables to help explain some of the external, environmentally based factors related to one's assessed QOL.

The 1990 version of the Quality of Life Questionnaire (Schalock, Keith & Hoffman, 1990) represents a significant revision of the 1986 version. The 1990 version is based on the results of considerable research with the 1986 version and a significant shift in the conceptualization of QOL for persons with disabilities as reflected in the following four principles:

- QOL is essentially the same for persons with and without disabilities. Persons with and without disabilities want the same things in their lives and have the same needs for decision making and choices as other persons in society.
- QOL is basically a social phenomenon and a product primarily of interactions with others.
- QOL is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings.

. **QOL** is primarily a subjective phenomenon. Ultimately, it is how the individual perceives and evaluates his own situation, rather than how others see him, that determines the **QOL** he or she experiences.

The 1990 **QOL** Questionnaire, which is attached as Appendix A,

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Refer to Appendix A

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reflects two years of development work involving 870 adults with disabilities in the United States and four other countries (Australia, Federal Republic of Germany, Israel and The Republic of China). During that time, both a field test and final version of the Questionnaire were administered to these persons to establish wording, format, item and factor analyses, reliability, and validity. Factor analyses on the 1990 QOL Qustionnaire's items indicate the following four factors:

1. **Satisfaction**, which is the fulfillment of a need or want, and the happiness or contentment that accompanies that fulfillment. Specifically, satisfaction relates to life in general, fun and enjoyment, personal experiences and feeling about one's general living/social situations.

2. **Competence/productivity**, as reflected in income-producing work or work that contributes to a household or community.

3. **Empowerment/Independence**, as reflected in the opportunity to exert control over one's environment, make decisions, and pursue choices.

4. **Social Belonging/Community Integration**, as reflected in participation in community activities, the use of community resources, and the development and experiencing of social contacts and relations.

Cross-Cultural Sample

Data were collected on 92 persons in MR/DD programs outside the United States, and 552 from MR/DD programs within Nebraska and Colorado. Colleagues in Australia, Germany, Israel, and The Republic of China were asked to select a representative sample within their respective program. Demographic characteristics on these service recipients are summarized in Table 1. This sample should not be considered

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Refer to Table 1

Table 1

Description of Cross-Cultural Sample

Variables	Country and Sample Size				
	Australia (N=18)	Federal Republic of Germany (N=11)	Israel (N=10)	Republic of China (N=53)	USA (N=552)
Age	28.4	43.4	30.6	23	37.8
Gender (%)					
Female	50		40	50.9	46.8
Male	50	100	60	49.1	53.2
Marital Status (%)					
Never Married	88.8	100	100	100	95.4
Married	5.6				4.2
Divorced	5.6				0.4
Average Total Income	$5847.	$1888.	$2310.	$1459.	$4704.
Primary Health Impairment (%)					
Cognitive	88.9	100	90	73.6	97.2
Sensory/Neurological			10	11.3	1.1
Physical	11.1			11.3	0.9
Emotional				3.8	0.8
Current Living Environment (%)					
Independent	61.1				19.2
Semi-independent	27.8		90	13.2	38.0
Supervised	11.1		10	75.5	42.8
Specialized Facility		100		11.3	
Current Work Status (%)					
Regular Employment	11.1				11.6
Employment With Ongoing Support	5.6		50	20.8	17.9
Sheltered	55.6	55	50	24.5	61.6
Unemployed	22.2	18		54.7	7.9
Retired	5.6	27			1.0
Educational Program (%)					
Public Education	17.6	27.3	10		6.3
MR/DD Services or Special Schools	41.2	72.7		100	87.2
No formal education or Training	41.2		90		6.5

reflective of the country as a whole, but merely those programs sampled. Generally speaking, across countries, the sample is evenly split between females and males in their 30s, never married, low income (income shown in Table 1 is in U.S. dollar equivalents), primarily cognitively impaired, living primarily in semi-independent or supervised environments and working in supported employment sites or sheltered workshops, and educated primarily in MR/DD services or special schools.

Cross-Cultural QOL Measures

The 1990 QOL Questionnaire was translated into Chinese (Mandarin), Hebrew and German (Australia used the U.S. version) prior to its administration. Directions to the administrators were that,

> If the person is verbal, have him/her answer each of the following questions acccording to how he/she honestly feels. Help the person with any word(s) that is (are) not understood. If the person is nonverbal, have <u>two</u> staff independently evaluate the person on each item and use the average score for each item.

The resulting QOL scores were analyzed in two ways. The first was to merely summarize them for each country per factor. These average QOL scores are presented in Table 2. We present

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Refer to Table 2

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these data only for discussion and hypothesis-generating purposes, and not for comparative purposes. Remember that the current sample is both small and non-representative.

Table 2

Quality of Life Factor Scores[a]

Factor	Country				
	Australia	Federal Republic of Germany	Israel	Republic of China	Nebraska/Colorado
Satisfaction	22.7(±4.1)[a]	22.2(±2.4)	23.2(±3.2)	18.3(±3.1)	21.8(±3.7)
Competence/ Productivity	19.5(±6.4)	17.5(±4.7)	24.2(±3.1)	15.0(±5.7)	21.2(±4.1)
Empowerment/ Independence	24.6(±4.1)	19.5(±1.6)	21.0(±2.7)	15.5(±3.7)	21.7(±3.6)
Social Belonging/ Community Integration	21.7(±3.9)	19.4(±2.0)	20.4(±2.9)	16.5(±3.2)	20.7(±2.9)
TOTAL	**88.4(±12.4)**	**78.8(±6.4)**	**88.8(±6.9)**	**65.4(±13.1)**	**85.3(±12.9)**

[a] These scores should be read with the small sample size in mind and the living-work environments of the sample (see Table 1).

The second way that the data were analyzed was to compare regardless of the country QOL scores across different living and work environments. These data, which are much more important to our current level of sophistication in cross-cultural QOL studies, are presented in Table 3 and Figure 3. There is a very

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Refer to Table 3 and Figure 3

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consistent trend found across the five countries in these data: QOL scores increase as one lives and works in more normalized environments. Additionally, the consistency among specific factor scores among the countries was striking.

The Concept of QOL In Habilitation Services

As mentioned in the introductory section, this study represents a first generation attempt to obtain cross-cultural measures of QOL based upon persons' perceptions of their degree of satisfaction, productivity, independence and community integration. In this final section of this presentation, we would like to share some thoughts about the concept of quality of life in habilitation services. These thoughts reflect both our work with the QOL concept, and the concern which many consumers and practitioners alike have that conditions of quality in the living, work and community integration lives of persons with disabilities are not changing fast enough to keep up with the rapid and wide-scale changes in people's attitudes, aspirations and values. As W.R. Shea (1976) suggests in an

Table 3

Average QOL Factor Scores Across Environments

Environment	QOL Factor Score			
Living[a]	Satisfaction	Competence/ Productivity	Empowerment/ Independence	Social Belonging/ Community Integration
Independent	23.1	-[b]	25.3	21.9
Semi-Independent	22.4	-	22.2	21.5
Supervised	20.3	-	17.7	18.8
Specialized	18.1	-	15.0	15.8
Employment				
Regular	24.9	26.5	-[c]	24.0
Employment with Supports	21.9	23.6	-	21.0
Sheltered	21.1	19.0	-	19.4
Unemployed	18.6	11.2	-	16.7

[a] Independent (rents/owns home, apartment); semi-independent (in a home setting, but with some supervision); supervised (eg., group home, lives with parents); specialized facility (hospital, nursing home, institution)

[b] Conceptually, competence/productivity relates to employment only.

[c] Conceptually, empowerment/independence relates primarily to the living environment.

Figure 3. Average Quality of Life Factor Scores Across Living-Work Environments

essay entitled, "The Quest For A High Quality Of Life:"

> What lends a sense of urgency to the quest...is the perverse feeling that time is running out, not only for philosophers, political scientists, and sociologists, but for politicians [and practitioners] as well (p.1)...

How might the concept of quality of life and measures reflecting it be used cross-culturally in habilitation services? We suggest three uses including: (1) fostering internationally QOL-oriented public policy; (2) implementing QOL-oriented program practices; and (3) completing QOL-focused cross-cultured research projects.

1. QOL-oriented public policy. Ultimately, the concern for an enhanced quality of life for persons with disabilities must be supported by federal, state and local policies and entities. We feel that the quality of life concept can serve as the basis for a more coherent and unified disability policy nationally and internationally, since QOL captures a broad array of issues and concerns that are important to persons with disabilities, their families, professionals, and governmental officials who administer programs and set policy. Because QOL is a generic concept, enhanced QOL outcomes for persons with and without disabilities are the same. Thus a QOL-oriented disability policy would be based on the same social expectations and goals that society holds for non-disabled citizens. In that sense, it is informative to compare those countries involved in the current cross-cultural study on their current public laws and policy, funding patterns, and administrative structure. These comparisons are summarized in Table 4.

Refer to Table 4

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2. QOL-oriented program practices. Using the QOL concept in planning habilitation services for persons with disabilities cannot be separated from the three major trends that are currently impacting service delivery systems throughout the world. In their simplest form, the trends include living, learning and working in integrated environments; empowering persons with disabilities to choose and make decisions regarding their welfare and future; and holding service providers accountable for person-referenced outcomes that reflect enhanced independence, productivity, community integration and quality of life.

Our feeling is that an enhanced quality of life for persons with disabilities is not likely to be achieved without a significant reorientation of the current service delivery system. The reorientation should be built on a set of QOL-oriented values, with specific QOL-oriented program practices outlined in Table 5.

Refer to Table 5

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3. Cross-cultural research. One of the major advantages and potential uses of standardized QOL measures is the important role they can play in research efforts. These efforts are just

Table 4

Cross-Cultural Comparisons of Public Laws/Policy, Funding Patterns and Administrative Structure

Country	Major Public Laws/Policy	Funding Patterns	Administrative Structure
Australia	Disability Services Act of 1986 - least restrictive alternative - principles that maximize the independence, rights & dignity of people with disabilities	- target groups include broad disability - eligible organizations include incorporated not for profit organization, tertiary institutions, local government, incorporated self interest groups	- primarily through the state (regions and country devisions) - some non-governmental agencies (parent/church) - smaller specialist or local community based agencies starting to appear
Federal Republic of Germany	Basic Law of the Federal Republic of Germany - disabled people are entitled to the same basic rights as others Social Code, Book I - social rights to integration assistance Rehabilitation Adjustment Act - funds for rehabilitation and integration Severely Disabled Persons Act - integration of severely disabled persons into employment, working life, and society	Residential Services - community-based = local (private, not for profit/ not for profit/state) - institutions - state or churches Vocational training-federal/ local Schools - local/state	- primarily through state and local governments - some church/private services
Israel	National Insurance Law of 1954 - every person has the right to vocational rehabilitation Social Welfare Act of 1958 - personal social services and rehabilitation services	Ministry of Labor and Social Affairs - provides 75% of the budget for all services delivered by the municipalities National Insurance Institute - benefit payments Voluntary organizations (eg., Hameshakem Ltd.)	Ministry of Labor and Social Affairs - deals with planning, funding and management of facilities Rehabilitation Services Admin. - supervises programs for persons with severe disabilities living in the community

Table 4 (continued)

Country	Major Public Laws/Policy	Funding Patterns	Administrative Structure
			The Foundation of Rehabilitation Enterprises - operates vocational and employment rehabilitation services Services for The Retarded - determine policy - supervises facilities (public and private)
Republic of China	Law of Special Education (1984) - right to education (6-15) - established special education programs Law for the Welfare of the Handicapped Persons (1989) - assist to live independently and work - stresses barrier free environments	Central Government - funds schools and institutions Private Providers - assess parents/clients - if program is registered with the government, parents can apply for government funds	Ministry of Education - Social Education Dept. - National Special Education Committee Ministry of Interior - Social Affairs Dept. Provincial Level - Commission of Education - Social Affairs Dept. Country and City - Education Dept. - Social Welfare Dept.

Table 5

QOL Factors and QOL-Oriented Program Practices[a]

Factor	Suggestions To Maximize The QOL Factor
Satisfaction	Encourage person, family, advocate's input to IPP
	Ask the person to evaluate personal satisfaction with the services received
	Build successes and positive feedback into habilitation environments
	Maximize the amount of disposable income that is under the person's control
	Safeguard and promote the physical quality of the home
	Promote quantity and quality of person's possessions
	Stress and allow for valued social roles and activities
Competence/Productivity	Develop basic abilities in communication, mobility, self-help and social leisure skills
	Develop functional living and employment skills
	Use prosthetics and environmental accomodation to reduce relevant mismatches between persons and their living-work environment
Empowerment/Independence	Allow choices over home, employment, activities, possessions and community activities
	Safeguard the person's health, nutrition and fitness
	Ensure adequate medical, dental, optical, physical therapy and nutritional services
Social Belonging/Community Integration	Promote access to community such as shops, leisure facilities and places of education
	Encourage a range of friends, family members, colleagues and peers

[a] Adapted from Blunden (1988), O'Brien (1987) and Schalock and Kiernan (1990)

now appearing in the international disabilities field (Donegan & Potts, 1988; Dossa, 1989; Reiss, 1989). We feel that there is a definite need to conduct research studies regarding quality of life, focusing on at least the following four important research questions:

- Correlate objective and subjective QOL measures.
- Evaluate interventions that improve both objective and subjective QOL scores.
- Determine whether improvements in one area effect improvements in another. For example, is a person's QOL improved through empowerment, employment, and/or least restrictive alternatives?
- Determine which models and factors of QOL for disabled persons apply to other populations.

A set of principles to guide these research efforts is presented in Table 6.

Refer to Table 6

In summary, there are many persons with disabilities throughout the world who are expressing a new way of thinking about people with disabilities. They are beginning to develop personal futures plans that include personal relationships, positive roles in the community, and increased control over their lives. Never before has the concept of quality of life been a more important issue in the field of disabilities than it

Table 6

QOL Principles To Guide Research Efforts

1. The study of QOL requires an indepth knowledge of people and their perspectives.
2. The study of QOL for people labeled mentally retarded or disabled requires that the label be set aside.
3. The measurement of QOL should be tied to values and linked to measures of QOL for all the nation's citizenry.
4. The measurement of QOL requires multiple methodologies.
5. Family assessments that are driven by family choices, and that are flexible, non-judgmental, and emphasize the development of family strengths need to be developed.
6. The application of QOL data is important in developing resources and supports for persons with disabilities and their families.

is today. It is our strong belief that the work and framework presented in this initial approach to QOL measurement will not guarantee an increased quality of life for persons with disabilities, but rather a method of asking questions to help evaluate the quality of life experience. In that sense, we hope that this and subsequent efforts will be viewed as a tool to work more creatively at public policy, service design, service delivery and program evaluation.

References

Andrews, F.R. & Whithey, S.B. (1976). Social indicators of well-being: Americans' perceptions of life quality. New York: Plenum Press.

Blunden, R. (1988). Programmatic features of quality services. In M.P. Janicki, M.W. Krauss & M.M. Seltzer (eds.), Community residences for persons with developmental disabilities: Here to stay (pp. 117-122). Baltimore: Paul H. Brookes Publishing Company.

Campbell, A., Converse, P.E. & Rogers, W.L. (1976). The quality of American life: Perceptions, evaluations and satisfactions. New York: Russell Sage Foundation.

Donegan, C. & Potts, M. (1988). People with mental handicaps living alone in the community. The British Journal of Mental Subnormality, 34(66), 10-21.

Dossa, P.A. (1989). Quality of life: Individualism or holism? A critical review of the literature. International Journal of Rehabilitation Research, 12(2), 121-136.

Goode, D.A. (1988). Quality of life for persons with disabilities: A look at the issues. Final report for a conference held in Washington, DC. April 30-May 1, 1988.

Keith, K.D., Schalock, R.L., & Hoffman, K. Quality of life questionnaire: 1986 version. Lincoln, NE: Region V Mental Retardation Services.

Lehman, A.F. (1988). A quality of life interview for the chronically mentally ill. Evaluation and Program Planning, 11, 51-62.

Milbrath, L.W. (1982). A conceptualization and research strategy for the study of ecological aspects of the quality of life. Social Indicators Research, 10, 133-157.

O'Brien, J. (1987). A guide to life-style planning. Using the activities catalog to integrate services and natural support systems. In B. Wilcox and G.T. Bellamy (eds.) A comprehensive guide to the activities catalog (pp. 175-189). Baltimore: Paul H. Brooks Publ. Co.

Reiss, S. (1989). Cross-cultural images of mental retardation. AAMR News and Notes, 2(6), 6.

Schalock, R.L. (1990). Quality of life: Perspective and issues. Washington, D.C.: American Association on Mental Retardation.

Schalock, R.L., Keith, K.D. & Hoffman, K. (1990). Quality of life standardization manual. Hastings, NE: Mid-Nebraska Mental Retardation Services, Inc.

Schalock, R.L., Keith, K.D., Hoffman, K. & Karan, O.C. (1989). Quality of life: Its measurement and use in human service programs. Mental Retardation, 27(1), 25-31.

Schalock, R.L. & Kiernan, W.E. (1990). Habilitation planning for adults with disabilities. New York: Springer Verlag.

Shea, W.R. (1976). The quest for a high quality of life. In J. Farlow and W.R. Shea (eds.), Values and the quality of life (pp. 1-5). New York: Science History Publications.

Footnotes

[a] Authors' affiliations and mailing addresses include:

Bartnik, Edward	AUTHORITY FOR INTELLECTUALLY HANDICAPPED PERSON-SOUTHWESTERN REGION 22 Queen St. (2nd Floor), PO Box 912 Fremantle, Western Australia 6160
König, Andreas	Vocational Rehabilitation Branch Training Dept., International Labour Office Bureau International Du travail CH 1211 Geneve 22, Switzerland (Dr. König's work is independent from -- and does not necessarily reflect -- that of the International Labor Office)
Lee, Chun-Shin	Director-Vocational Training Center for the Mentally Retarded 77, Yu-Ying Rd., Chung-Li Taiwan, R.O.C.
Reiter, Shunit	School of Education University of Haifa Mt. Carmel, Haifa 31 999, Israel
Schalock, Robert L.	Hastings College and Mid-Nebraska Mental Retardation Services Box 1146 Hastings, NE 68901
Wu, Fang	SHUANG CHI FOUNDATION FOR MENTALLY RETARDED CHILDREN No. 2, Alley 81, Lane 113, Section 2 Chih Shan Rd., ShinLin District Taipei, Taiwan, 111, R.O.C.

APPENDIX A

QUALITY OF LIFE QUESTIONNAIRE: RESPONDENT DEMOGRAPHIC PROFILE
(1990 VERSION)

Person's Name: _____ Age: _____ Gender: Male : _____ Female: _____
City/State/ Country: _____
Marital Status: Single, Never Married : _____ Married : _____ Divorced: _____ Widow/ Widower: _____
Highest educational grade completed: _____ Approximate total income (in thousands) _____

Current Health Condition (Check the category that best describes the person) :

_____ Chronic health impairment (heart, diabetes, arthritis, emphysema)
_____ Intellectual impairment (mental retardation)
_____ Sensory/Neurological impairment (epilepsy, traumatic brain injury)
_____ Physical impairment (cerebral palsy)
_____ Emotional impairment (autism, mental illness)
_____ No major health impairment

Current Living/Work/Educational Status [check one in each (a, b, c) section]

a. Living
_____(1) Independent (rents/owns home, apartment)
_____(2) Semi-independent (in a home setting, but with some supervision)
_____(3) Supervised (e.g., group home)
_____(4) Specialized facility (hospital, nursing home, institution)
For which ever one checked, for how long have you lived in this arrangement? _____ (years)

b. Work
_____(1) Regular employment (self employed, part-time, full-time)
_____(2) Employed, but received ongoing support
_____(3) Sheltered/segregated work (e.g., sheltered workshop)
_____(4) Unemployed (check one)
_____ (a) not seeking employment (e.g. homemaker)
_____ (b) seeking or has sought employment
_____(5) Retired
For which ever one checked, for how long have you been doing it? _____ (years)

c. Educational Program
_____(1) Public education (community college, GED, continuing education)
_____(2) MR/DD related educational/training services
_____(3) No formal educational/training services

QUALITY OF LIFE QUESTIONNAIRE
(1990 Version)

NAME: _____ DATE: _____ EVALUATOR/RESPONDENT_____

Directions: If the person is verbal, have him/her answer each of the following questions according to how he/she honestly feels. Help the person with any word(s) that is (are) not understood. If the person is nonverbal, have two staff independent evaluate the person on each item and use the average score for each item. Each of the four quality of life factors (satisfaction, competence/productivity, empowerment/independence and social belonging/community integration) is scored separately. The range is 10-30 per factor. A total score is obtained by simply adding the four factor scores.

Quality of Life Factor Scores
Satisfaction: _____
Competence/Productivity: _____
Empowerment/Independence: _____
Social Belonging/Community Integration: _____
Total Score: _____

Question	Scoring Categories		
SATISFACTION	3	2	1
1. Overall, would you say that life:	Brings out the best in you _____	Treats you like everybody else _____	Doesn't give you a chance chance _____
2. How much fun and enjoyment do you get out of life?	Lots _____	Some _____	Not much _____
3. Compared to others, are you better off, about the same, or less well off?	Better _____	About the same _____	Worse _____
4. Are most of the things that happen to you:	Rewarding _____	Acceptable _____	Disappointing _____
5. How satisfied are you with your current home or living arrangement?	Very Satisfied _____	Somewhat satisfied _____	Unsatisfied or very unsatisfied _____
6. Do you have more or fewer problems than other people?	Fewer problems _____	The same number of problems as others _____	More problems than others _____

Question	Scoring Categories		
	3	2	1
7. How many times per month do you feel lonely?	Seldom, never more than once or twice _____	Occasionally, at least 5 or 6 times a month _____	Frequently, at least once or twice a week _____
8. Do you ever feel out of place in social situations?	Seldom or never _____	Sometimes _____	Usually or always _____
9. How successful do you think you are, compared to others?	Probably more successful than the average person _____	About as successful as average person _____	Less successful than the average person _____
10. What about your family members? Do they make you feel:	An important part of the family _____	Sometimes a part of the family _____	Like an outsider _____

Satisfaction Score: _____
(Range 10-30)

COMPETENCE/PRODUCTIVITY

11. How well did your educational or training program prepare you for what you are doing now?	Very well _____	Somewhat _____	Not at all well _____
12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?	Yes, definitely _____	Probably _____	I'm not sure, or definitely not _____

NOTE: **If a person is unemployed, do not ask Questions 13-20. Score items #13-20 "1"**

13. How good do you feel you are at your job?	Very good, and others tell me I am good _____	I'm good, but no one tells me _____	I'm having trouble on my job _____
14. How do people treat you on your job?	The same as all other employees _____	Somewhat differently than other employees _____	Very differently _____
15. How satisfied are you with the skills and experience you have gained or are gaining from your job?	Very satisfied _____	Somewhat satisfied _____	Not satisfied _____

Question	Scoring Categories 3	2	1
16. Are you learning skills that will help you get a different or better job? What are these skills?	Yes, definitely (One or more skills actually mentioned) _____	Am not sure, maybe (vague, general skills mentioned)_____	No, job provides no opportunity for learning new skills _____
17. Do you feel you receive fair pay for your work?	Yes, definitely _____	Sometimes _____	No, I do not feel I am paid enough _____
18. Does your job provide you with enough money to buy the things you want?	Yes, I can generally buy those reasonable things I want _____	I have to wait to buy some items or not buy them at all _____	No, I definitely do not earn enough to buy what I need _____
19. How satisfied are you with the benefits you receive at the workplace?	Very satisfied _____	Somewhat satisfied _____	Not satisfied _____
20. How closely supervised are you on your job?	Supervisor is present only when I need him or her _____	Supervisor is frequently present whether or not I need him or her ____	Supervisor is constantly on the job and looking over my work _____

Competence/Productivity Score : _____
(Range 10-30)

EMPOWERMENT/INDEPENDENCE

21. How did you decide to do the job or other daily activities you do now?	I chose it because of pay, benefits, or interests _____	Only thing available or that I could find _____	Someone else decided for me _____
22. Who decides how you spend your money?	I do _____	I do, with assistance from others _____	Someone else decides _____
23. How do you use health care facilities (doctor, dentist, etc.)?	Almost always on my own _____	Usually accompanied by someone, or someone else has made the appointment _____	Never on my own _____
24. How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?	Complete _____	Some _____	Little _____

Question	Scoring Categories		
	3	2	1
25. When can friends visit your home?	As often as I like or fairly often _____	Any day, as long as someone else approves or is there _____	Only on certain days _____
26. Do you have a key to your home?	Yes, I have a key and use it as I wish _____	Yes, I have a key but it only unlocks certain areas _____	No _____
27. May you have a pet if you want to?	Yes, definitely _____	Probably yes, but would need to ask _____	No _____
28. Do you have a guardian or conservator?	No, I am responsible for myself _____	Yes, limited guardian or conservator _____	Yes, I have a full guardian _____
29. Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry?	No ___	Yes, and those problems occur once a month or once a week _____	Yes, and those problems occur every day or more than once a day _____
30. Overall, would you say that your life is:	Free _____	Somewhat planned for you _____	Cannot usually do what you want _____

Empowerment/Independence Score: _____
(Range 10-30)

SOCIAL BELONGING/COMMUNITY INTEGRATION

31. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?	2-3 _____	1 only _____	None _____
32. How satisfied are you with the clubs or organizations (including church or other religious activities) to which you belong?	Very satisfied _____	Somewhat satisfied _____	Unsatisfied or very unsatisfied _____

Question	Scoring Categories		
	3	2	1
33. Do you worry about what people expect of you?	Sometimes, but not all the time _____	Seldom _____	Never or all the time _____
34. How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?	3-4 times per week _____	1-2 times per week _____	Seldom 1-2 times per month or less _____
35. Do you have friends over to visit your home?	Fairly often _____	Sometimes _____	Rarely or never _____
36. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?	3-4 per month _____	1-2 per month _____	Less than 1 per month _____
37. Do you participate actively in those recreational activities?	Usually, most of the time _____	Frequently, about half the time _____	Seldom or never _____
38. What about opportunities for dating or marriage?	I am married, or have the opportunity to date anyone I choose _____	I have limited opportunities to date or marry_____	I have no opportunity to date or marry _____
39. How do your neighbors treat you?	Very good or good (invite you to activities, coffee, etc.) _____	Fair (Say hello, visit, etc.) _____	Bad or very bad (avoid you, bother you, etc.) _____
40. Overall, would you say that your life is:	Very worthwhile ____	Okay _____	Useless _____
Social Belonging/ Community Integration Score: _____ (Range 10-30)			

Please consult the 1990 Quality of Life Questionnaire Standardization Manual (R.L. Schalock, K.D. Keith & K. Hoffman) for reliability, validity, normative data, and suggested uses of QOL Questionnaire data. The Manual is available from Mid-Nebraska Mental Retardation Services, Inc. P.O. Box 1146, Hastings, Nebraska 68901 (402-462-5107)